

A NATIONAL GOAL

Building Service Delivery Systems

For Children With

Special Health Care Needs

And Their Families

Family Centered, Community Based,

Coordinated Care

A NATIONAL GOAL

In 1987 the Surgeon General of the United States enunciated as a national goal the promotion of family-centered, community-based, coordinated care for children with special health care needs and their families. This concept is likewise reflected in recently enacted federal legislation.

In order to make the concept of family-centered, community-based, coordinated care a reality, it is necessary to build systems of the delivery of health services and a variety of other services to children with special health care needs and their families that incorporate this concept. A services delivery system may be defined as an organized network of services. The creation of such an organizational infra-structure promotes the institutionalization of family-centered, community-based, coordinated care, and it assures its continuance over time.

The building of a service delivery system requires an understanding of the elements of such a system. The building of a service delivery system also requires an understanding of the steps that should be taken to develop such a system.

ELEMENTS OF THE SERVICE SYSTEM

1. The service delivery system should serve a broad population of children with special health care needs who have health problems requiring something beyond routine and basic care.
 - The system should serve children with disabilities and handicapping conditions.
 - The system should serve children with chronic illnesses and conditions.
 - The system should serve children with health related educational problems.
 - The system should serve children with health-related behavior problems.
 - The system should serve children at risk for disabilities, chronic conditions and health related educational and behavioral problems.
 - The system should serve families of children with special health care needs

The service delivery system, with its focus on serving a broad population of children with special health care needs and their families, reflects a generic orientation rather than a disease-specific or condition-specific orientation. It is simply not feasible from the standpoint of personnel availability and cost to have a number of separate service delivery systems for children with different diseases and conditions. In addition the generic orientation is an outgrowth of a recognition that children with different diseases and conditions need disease-specific or condition-specific services, but they also have a common life experiences and problems stemming from the generic dimensions of their diseases and conditions.

2. The service delivery system should make available and accessible comprehensive services for both children with special health care needs and their families.
 - The system should make available and accessible, to children with special health care needs, health services. These services include primary level basic care, secondary level specialized care and tertiary level highly specialized care provided by a combination of community-based physicians and clinics, other health care providers, regional medical centers and clinics and tertiary medical centers and clinics.
 - The system should make available and accessible, to children with special health care needs, other needed services and programs, including:
 - * early intervention,
 - * educational services,
 - * vocational services,
 - * mental health services,
 - * social services, and
 - * recreational and arts programs

- The system should make available and accessible, to families of children with special health care needs, family support services, such as parent-to-parent support and respite care.

Because children with special health care needs and their families often have a variety of problems, they often require a range of different types of services. Hence, the service delivery system should have several different service components to assure that these children and their families receive the range of needed services.

3. The service delivery system should be community based.

- The system should to the extent possible provide needed services to children with special health care needs and their families in or near their home communities.
- The relevant geographic area for the purpose of developing a service delivery system will vary widely between states and within a state.

The call for a service delivery system that provides community-based services is a response to the fact that all too often needed services are not available or accessible in or near the home communities of children with special health care needs and their families. Delivery of needed services in or near the home communities of children with special health care needs and their families facilitates the ability of families to care for their children at home and promotes normal patterns of living.

The geographic area covered by a service delivery system will depend on a number of factors, including population density, political subdivisions, existing arrangements for provision of services, and the availability of resources. For example, a service delivery system may cover several counties in a rural area or a neighborhood in a large urban area.

4. The service delivery system should provide services that are coordinated.

- The system should provide multiple services from different providers in a complementary and consistent manner.
- The system should provide multiple services from different providers in a timely manner.
- The system should provide multiple services from different providers in the proper sequence.

The call for a service delivery system that provides services that are coordinated is a response to the fact that children with special health care needs and their families generally require multiple services from different providers associated with different agencies, institutions, and organizations and that these services are highly fragmented. It has been well documented that the many public and private programs serving these children and their families have differing mandates, differing eligibility requirements and inconsistent policies, and as a result, there are gaps and duplications in services.

5. The service delivery system should provide services that are family centered.
- The fact that the family is the constant in the child's life while the service system and personnel within that system fluctuate should be recognized.
 - Parent/professional collaboration at all levels should be facilitated.
 - Unbiased and complete information about their child's care should be shared with parents on an ongoing basis in an appropriate and supportive manner.
 - Appropriate policies and programs that are comprehensive and provide emotional and financial support to meet the needs of families should be implemented.
 - Family strengths and individuality should be recognized, and different methods of coping should be respected.
 - The developmental needs of infants, children and adolescents and their families should be recognized and incorporated into the system.
 - Parent-to-parent support should be encouraged and facilitated.
 - The design of the system should be flexible, accessible, and responsive to family needs.

The call for a service delivery system that provides family-centered services is an outgrowth of the recognition of the importance of the family in the child's life. Thus, family-centered services support and assist families in their natural and pivotal role as the primary caretakers of their children by involving families and professionals as equal partners in the care of children.

STEPS IN SERVICE SYSTEM DEVELOPMENT

1. Communities should assume major responsibility for planning, designing, and implementing service delivery systems.
 - A process for systems development should be instituted at the local level involving representatives of a variety of groups, including: (1) community health care providers, (2) providers of other needed community services, (3) families of children with special health care needs, (4) civil, religious and child advocacy organizations, and (5) local public officials and community leaders.
 - A community plan, based upon a needs assessment, should be developed and implemented.
 - Organizational mechanisms should be established and maintained at the local level to bring about collaboration among community service providers in the following areas:
 - *the planning of services,
 - *the delivery of services,
 - *the funding of services.
 - An organizational mechanism should be established and maintained for community-based case management including: (1) the development of a community plan of services for a child and his or her family by community providers of services, and (2) the implementation of the plan by an identified community service team, one of whom functions as a case manager.
2. State governments should assume responsibility for assisting communities to develop service delivery systems.
 - A statewide plan, based upon a needs assessment, should be developed at the state level for building service delivery systems for children with special health care needs through the collaborative efforts of all relevant state agencies.
 - All relevant state agencies should establish and maintain collaborative mechanisms for the purpose of providing guidance and assistance to communities in the process of system development including: (1) establishment of state policies to facilitate system development, (2) establishment of minimum standards for service systems, (3) provision of technical assistance and consultation to communities, (4) development of education and training materials and programs for communities, (5) provision of financial resources to communities for systems development, and (6) evaluation of service systems.

Service delivery systems must be developed at the local level, and both state governments and communities have central and crucial roles to play in system development.

There are a variety of models for service delivery systems. The service delivery systems actually developed will vary from state-to-state and from locality-to-locality within a state because

of differences among states and localities with respect to their specific service delivery system needs.

It should also be noted that a service delivery system of can and should evolve from the creation and the expansion of collaborative arrangements between existing programs providing particular sets of services for particular categories of children with special health care needs. In some cases it may be necessary or desirable to build a service delivery system by establishing a system the initial focus of which is one or more types of services for one or more types of children with special health care needs and then expanding the system so as to encompass other services and other children with special health care needs.

The federal Maternal and Child Health Bureau (MCHB) has undertaken a number of major initiatives to promote development of service delivery systems incorporating the concept of family-centered, community-based, coordinated care. For further information contact:

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